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## Prevalence of Pre-existing Conditions Among Community Health Center Patients Before and After the Affordable Care Act

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### Abstract

**Objective:** To assess the prevalence of pre-existing conditions for community health center (CHC) patients who gained insurance coverage post-Affordable Care Act (ACA).

**Methods:** We analyzed electronic health record data from 78,059 patients aged 19 to 64 uninsured at their last visit pre-ACA from 386 CHCs in 19 states. We compared the prevalence and types of pre-existing conditions pre-ACA (2012 to 2013) and post-ACA (2014 to 2015), by insurance status and race/ethnicity.

**Results:** Pre-ACA, >50% of patients in the cohort had 1 Pre-existing condition. Post-ACA, >70% of those who gained insurance coverage had 1 condition. Post-ACA, all racial/ethnic subgroups showed an increase in the number of pre-existing conditions, with non-Hispanic Black and Hispanic patients experiencing the largest increases (adjusted prevalence difference, 18.9; 95% CI, 18.2 to 19.6 and 18.3; 95% CI, 17.8 to 18.7, respectively). The most common conditions post-ACA were mental health disorders with the highest prevalence among patients who gained Medicaid (45.6%) and lowest among those who gained private coverage (30.5%).

**Conclusions:** This study emphasizes the high prevalence of pre-existing conditions among CHC patients and the large increase in the proportion of patients with at least 1 of these diagnoses post-ACA. Given how common these conditions are, repealing pre-existing condition protections could be extremely harmful to millions of patients and would likely exacerbate health care and health disparities.

### Keywords

Chronic Disease; Cohort Studies; Community Health Centers; Electronic Health Records; Health Care Reform; Health Policy; Insurance Coverage; Medicaid; Medically Uninsured; Patient Protection and Affordable Care Act; pre-existing Condition Coverage

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The Patient Protection and Affordable Care Act (ACA) was enacted to improve access to health care and reduce health disparities.<sup>1</sup> Several of the provisions legislated to meet these goals included increasing availability of health insurance to all citizens and permanent residents of the United States, requiring health insurance plans to provide essential benefits, and ensuring that individuals with a pre-existing health condition could not be denied coverage or charged more for premiums.<sup>2</sup>

The ACA expanded coverage options through a Medicaid eligibility expansion to individuals earning 138% of the federal poverty level, which was implemented in over half of US states, and developed a health insurance marketplace and subsidies for some individuals to purchase private coverage. Before this provision, Medicaid eligibility was very restrictive, and it was difficult to purchase individual health insurance plans.

The ACA also required all health insurance plans to provide essential health benefits covering ambulatory, laboratory, and preventive services; chronic disease management; and mental health and substance use disorder treatment.<sup>2</sup> Whereas, before the ACA, health insurance companies could design their own benefit plans that omitted or restricted covered services, especially for behavioral and mental health.

In addition, after 2010 health insurers could no longer deny coverage or require higher premiums for those with a pre-existing condition. Before the ACA, most plans discriminated against people with a pre-existing condition and declined to offer them coverage or required them to pay significantly higher premiums than those without these conditions. A pre-existing condition is a health diagnosis that exists before someone tries to enroll in a new health insurance policy. Previous research estimated that nearly 27% of US adults aged 18 to 64 years had a declinable (ie, pre-existing) condition.<sup>3</sup> However, the estimated prevalence of pre-existing conditions in the United States is based on self-reported data of a population mostly covered via employer-sponsored health insurance. Thus, it is likely that the prevalence is different for those insured by Medicaid, the individual marketplace, or those without insurance. In addition, 20 million individuals gained coverage following the ACA, with subsequent increases in outpatient health care visits and preventive service receipt.<sup>4-6</sup> It is likely that this surge in utilization resulted in an increase in the prevalence of pre-existing conditions being identified and formally documented,<sup>7</sup> yet this hypothesis has not yet been tested and confirmed.

Understanding the prevalence of pre-existing conditions among vulnerable patients and how much it may have increased post-ACA has become even more urgent given recent policy proposals and court rulings, which could lead to the repeal of the ACA. For example, several repeal/replace initiatives have recommended the elimination of ACA provisions that protect patients with pre-existing conditions from discrimination by insurers. For policy makers to understand the reach of altering or repealing some or all the ACA provisions, we need to quantify the frequency of pre-existing conditions for those most impacted by health reform and how it changed pre- to post-ACA. Knowing the frequency of common diagnoses could also assist with future policy decisions around health care access and funding needs.

To quantify the prevalence of pre-existing conditions before and assess the change in the prevalence of patients with pre-existing conditions after the ACA implementation, we partnered with the Accelerating Data Value Across a National Community Health Center Network (ADVANCE) clinical data research network (CDRN) of community health centers (CHCs), a CDRN of PCORnet.<sup>8</sup> We selected this national network as CHCs serve patients most impacted by the ACA's health insurance opportunities. For example, in 2018, among the 28 million patients served by CHCs, 23% were uninsured, and 49% had Medicaid coverage.<sup>9</sup> CHC populations are also diverse and include many racial and ethnic minority patients: 35% Hispanic and 23% Black/African American.<sup>9</sup> In addition, CHCs serve patients with higher rates of chronic diseases such as diabetes and hypertension than the general population.<sup>9</sup> Finally, data from this network of CHCs include diagnoses during periods of time when patients are uninsured as well as when they are insured. Thus, we used these data to quantify the prevalence of pre-existing conditions among low-income patients before and after the ACA by insurance status and race/ethnicity.

## Methods

### Study Data

The dataset included 386 CHCs in 19 states (AK, CA, FL, HI, KS, MD, MN, MO, MT, NC, NM, NV, OH, OR, RI, TX, WA, WI). We constructed a cohort of established adult patients who gained insurance post-ACA. Each patient had 1 ambulatory visit in the pre-ACA period and 1 in the post-ACA period; we included patients who were uninsured at their last pre-ACA visit and then had 1 post-ACA visit with Medicaid or private insurance. The cohort was aged 19 to 64 years at their first post-ACA visit. We defined pre-ACA as January 1, 2012 to December 31, 2013 and post-ACA as January 1, 2014 to December 31, 2015.

This study was approved by the Institutional Review Board at our academic health center.

### Measures

Pre-existing conditions were identified by International Classification of Diseases, Ninth or Tenth Revision (ICD-9/10). Pre-existing conditions were based on a modified version of the Kaiser Family Foundation (KFF) list of common "declinable medical conditions" maintained by more than half of insurers,<sup>3</sup> which included HIV/AIDS; lupus; alcohol and drug abuse (excludes tobacco use); mental disorders (eg, depression, bipolar disorder); Alzheimer's/dementia; multiple sclerosis; rheumatoid arthritis, fibromyalgia, and other inflammatory joint disease; muscular dystrophy; cancer other than skin; severe obesity; cerebral palsy; congestive heart failure; paraplegia and paralysis; coronary artery disease; Crohn's disease and ulcerative colitis; Parkinson's disease; chronic obstructive pulmonary disease, emphysema, and asthma; diabetes mellitus; pneumocystic pneumonia; epilepsy; hemophilia; sleep apnea; hepatitis; stroke; and kidney disease/renal failure. The full list<sup>10</sup> includes additional conditions that are less common. We also excluded from the full list organ transplant, pending surgery/hospitalization, and transsexualism as these are difficult to reliably ascertain from our electronic health record (EHR) data. A condition was considered present in the pre-ACA period if it appeared on a patient's problem list or as an encounter diagnosis by December 31, 2013; similarly, post-period conditions were assessed as any

relevant diagnosis documented by December 31, 2015. Of note, we included pregnant women in this study but did not include pregnancy as 1 of the declinable conditions.

### Insurance Status

EHR data contain information on payer types for billing purposes at each visit; these data provide reliable information on insurance status. Insurance types were categorized as gained Medicaid (N = 50,839) which are patients with at least 1 Medicaid-paid visit post-ACA or private coverage (N = 27,220), which are patients with at least 1 private insurance paid visit post-ACA.

### Race/Ethnicity

CHCs are required to collect and report many individual-level demographic data to the Health Resources and Services Administration to receive funding or designation under the Health Center Program. Therefore, CHC EHRs contain self-reported data on race/ethnicity and language on nearly all patients.<sup>11</sup> We stratified results by the following race/ethnicity groups: non-Hispanic White (N = 29,764); Hispanic, if they identified as Hispanic or had Spanish listed as their primary language, (N = 30,296); or non-Hispanic Black (N = 13,090). The ADVANCE CDRN includes only 1 race and 1 ethnicity option.

### Statistical Analysis

We computed the prevalence of any of the assessed conditions, and the top 5 individual conditions, in the pre- and post-ACA periods, stratified by insurance coverage and race/ethnicity. We also estimated within-racial/ethnic and insurance type-group absolute prevalence differences of having at least 1 condition post versus pre-ACA with 95% CI estimates comparing post versus pre-ACA changes. For these estimates, we used generalized estimating equation models specifying a Gaussian distribution, identity link function, an independent working correlation matrix with robust standard errors and adjusted for sex, age, federal poverty level, expansion status of state, number of visits, race/ethnicity, insurance category, and health system. Standard errors were clustered by patient nested within their primary clinic to account for temporal correlation of observations within patients over the ACA periods and intracluster correlation of patients within clinics. In a sensitivity analysis, we compared the prevalence of pre-existing conditions in states that expanded versus did not expand Medicaid eligibility to control for differential in access to care (see Appendix 1 for results and methodology). Data analyses were conducted with SAS v. 9.4 (IBM, Armonk, NY).

## Results

### Pre-existing Conditions Pre- and Post-ACA by Insurance Type and Race/Ethnicity

We found that among the study cohort (patients who were uninsured pre-ACA and gained coverage post-ACA), over 51% were diagnosed with 1 pre-existing condition before the implementation of the ACA. Post-ACA, nearly 80% of those who gained Medicaid coverage and nearly 70% of those who gained private insurance had a documented diagnosis of at least 1 condition (adjusted prevalence difference, 16.8%; 95% CI, 16.5 to 17.2 for those who

gained Medicaid and 18.0%; 95% CI, 17.6 to 18.5 for those who gained private coverage; Table 1).

Pre-existing conditions were also prevalent in all racial and ethnic groups pre-ACA, with the highest proportion among non-Hispanic White patients (Table 1). Post-ACA, all 3 racial/ethnic groups showed a large increase in documented diagnoses of conditions, with non-Hispanic Black and Hispanic patients experiencing the largest increase (adjusted prevalence difference, 18.9; 95% CI, 18.2 to 19.6 and 18.3; 95% CI, 17.8 to 18.7, respectively).

### Types of Conditions Pre- and Post-ACA by Insurance Type and Race/Ethnicity

The most common diagnosed conditions among patients in the cohort were mental health disorders (Table 2) with the highest post-ACA prevalence among those who gained Medicaid (45.6%). In both gained-Medicaid and gained-private subgroups, the prevalence of alcohol/drug misuse nearly doubled post-ACA.

Prevalence of individual conditions also differed by racial and ethnic groups (Table 3). Specifically, in the pre-ACA period, non-Hispanic White patients were more likely to have diagnoses of alcohol and drug abuse, COPD/asthma, and mental health disorders, while non-Hispanic Black and Hispanic patients had higher prevalence of diabetes and obesity. Despite the overall higher rates of alcohol and drug abuse and mental health disorders for non-Hispanic White patients, the relative change in these diagnoses was greater for Hispanic and non-Hispanic Black patients. Specifically, diagnoses of alcohol and drug abuse nearly doubled post-ACA among Hispanic (pre-ACA, 3.4%; post-ACA, 6.2%) and non-Hispanic Black (pre-ACA, 8.5%; post-ACA, 15.1%) patients. The relative increase for mental health diagnoses were 52% for non-Hispanic Black patients and 44% for Hispanic patients. Changes in diagnosis of asthma/COPD, diabetes, and obesity from pre- to post-ACA were similar across the racial and ethnic groups.

Findings were similar when stratified by Medicaid expansion versus nonexpansion status (Appendix).

## Discussion

The ACA led to increased access to health care services for patients seen in CHCs.<sup>6,12</sup> This increase in access likely resulted in new diagnoses and treatment for chronic conditions. In our national cohort of CHC patients, we observed an increase from 58% of patient pre-ACA to 76% of patients post-ACA who had at least 1 diagnosis (now considered a pre-existing condition). Notably, this CHC patient population had a much higher prevalence (despite the reduced list of conditions) than what is estimated among the general population (27%).<sup>3</sup> Previous studies<sup>13,14</sup> have highlighted that uninsured individuals are less likely to receive preventive services and more likely to have undiagnosed conditions.<sup>15,16</sup> The surge in pre-existing conditions observed among this CHC patient population that gained insurance suggests that this cohort of patients had undiagnosed conditions and unmet health care needs before the ACA, and, demonstrate the importance of health insurance coverage to access needed care that results in diagnosis.

Mental and behavioral health conditions saw the sharpest increase in prevalence post-ACA. It is likely that these conditions existed pre-ACA but that patients had better access post-ACA, which enabled them to get more complete and accurate diagnoses. In the midst of the US opioid epidemic and the persistent contribution of alcohol abuse to significant morbidity and mortality in our nation, this finding represents a positive turn in the struggle to adequately treat these conditions. For example, CHCs have been shown to play a critical role in providing mental health and substance abuse treatment to low-income patients.<sup>17</sup> In addition, CHCs have increased the integration of mental and behavioral health providers, which facilitate access to services for their patients.

Since 2016, there have been many legislative proposals attempting to change or remove different provisions of the ACA including Medicaid expansion and pre-existing condition protections.<sup>18</sup> The ACA is also being challenged in the judicial system. The individual mandate now carries no financial penalty, in December 2018, a federal judge<sup>19</sup> ruled that the individual mandate was unconstitutional, and subsequently the ACA legislation has been deemed unconstitutional. Our findings suggest that the number of people with a documented pre-existing condition went up significantly post-ACA. Thus, rulings to weaken or repeal the ACA could lead to millions of adults losing coverage and unable to regain coverage (due to losing protection from discrimination based on pre-existing conditions). The number unable to regain coverage is likely even greater than it was during the period before the ACA because a higher percentage of these conditions are now formally documented. This population will be further disadvantaged if efforts to repeal other ACA provisions lead to contractions in Medicaid programs and/or loss of other insurance options. In addition, our findings suggest that repeal of the ACA may be most impactful for subpopulations of patients, such as those with alcohol and drug use disorders (including those with opioid use disorder). For those with opioid use disorders, access to treatment and appropriate medication are essential and without comprehensive coverage, patients may face difficulty accessing them, perpetuating the epidemic.

The study has limitations, as it is based on CHCs in 19 US states who are part of the ADVANCE network. Thus, our results may not generalize to CHC populations in all US states. However, the profile of CHC patients in the ADVANCE network is comparable to national estimates.<sup>9</sup> Uninsured patients who obtained health insurance post-ACA may have sought care outside of CHCs, which our data would not capture. However, evidence suggests that primary care providers outside of CHCs are not accepting or are significantly limiting the number of Medicaid-insured patients in their panels, and we have found that these patients largely stay within the CHC system after gaining insurance.<sup>20–22</sup> It is likely that the proportion of pre-existing conditions is underestimated as the shortened Kaiser Family Foundation (KFF) list is not comprehensive and excludes many common conditions that may affect insurance eligibility and premiums (eg, migraine headaches, chronic pain, hypertension, ulcers, and Gastroesophageal reflux disease [GERD]).

This study emphasizes the high prevalence of pre-existing conditions among a sizeable population of CHC patients and the marked increase in documentation of pre-existing conditions among CHC patients who gained coverage post-ACA. Our findings suggest that without continuation of this provision (especially if in concert with a reduction in health

insurance options), many Americans will likely face insurmountable barriers to obtaining health coverage and accessing health care services (especially for those with mental and behavioral health conditions). Though these changes are hypothetical at the present time, our study highlights the potential damaging effects repealing these important ACA provisions could have on the health of millions of patients who gained new coverage after ACA implementation.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1.** Prevalence of Pre-existing Conditions and Adjusted Comparisons, Among a Cohort of Established CHC Patients Pre- and Post-Implementation of the Affordable Care Act (ACA) Insurance Expansions in 2014, by Insurance Type and Race/Ethnicity

	N	Pre-ACA, n (%)	Post-ACA, n (%)	Adjusted Absolute Prevalence Difference, Post vs Pre-ACA (95% CI)
<b>Insurance type</b>				
Gained Medicaid	50,839	31,454 (61.9)	40,008 (78.7)	+16.8 (16.5, 17.2)
Gained Private	27,220	14,080 (51.7)	18,987 (69.8)	+18.0 (17.6, 18.5)
<b>Race/ethnicity</b>				
Non-Hispanic White	29,764	20,491 (68.8)	25,179 (84.6)	+15.8 (15.4, 16.2)
Hispanic	30,296	15,108 (49.9)	20,626 (68.1)	+18.3 (17.8, 18.7)
Non-Hispanic Black	13,090	7413 (56.6)	9827 (75.1)	+18.9 (18.2, 19.6)

CHC, community health center; CI, confidence interval.

Data from 386 community health centers in 19 states (AK, CA, FL, HI, KS, MD, MN, MO, MT, NC, NM, NY, OH, OR, RI, TX, WA, WI). The retrospective cohort of established patients included those who were uninsured at their last visit pre-ACA (2012 to 2013) and gained insurance coverage post-ACA (2014 to 2015). Conditions identified by ICD 9/10 codes in patients' problem lists or encounter diagnoses based on the Henry J Kaiser Family Foundation list of declineable conditions. We computed within-race/ethnicity and insurance type-group prevalence differences of having at least one pre-existing condition post- vs pre-ACA. Adjusted estimates obtained from generalized estimating equation models specifying a Gaussian distribution, identity link function, an independent working correlation matrix with robust standard errors and adjusted for sex, age, federal poverty level, number of visits, race-ethnicity (insurance type models), post-ACA insurance type (racial/ethnic models), state Medicaid expansion status, and health system. Standard errors were clustered by patient nested within their primary clinic to account for temporal correlation of observations within patients over the ACA periods and intracluster correlation of patients within clinics. Pre-post prevalence differences were significant ( $P < .001$ ) for all comparisons.

**Table 2.** Prevalence of Top 5 Conditions Pre- and Post-ACA, Among a Cohort of Established Community Health Center Patients Pre- and Post-Implementation of the Affordable Care Act (ACA) Insurance Expansions in 2014, by Insurance Type

	<u>Gained Medicaid (N = 50,839)</u>		<u>Gained Private (N = 27,220)</u>	
	Pre, n (%)	Post, n (%)	Pre, n (%)	Post, n (%)
Alcohol and drug abuse	6,005 (11.8)	10,067 (19.8)	1,087 (4.0)	2,084 (7.7)
Asthma and COPD	7,452 (14.7)	10,679 (21.0)	2,865 (10.5)	4,141 (15.2)
Diabetes	7,163 (14.1)	8,826 (17.4)	3,982 (14.6)	4,834 (17.8)
Mental health disorders	17,077 (33.6)	23,199 (45.6)	5,899 (21.7)	8,292 (30.5)
Obesity	8,523 (16.8)	12,972 (25.5)	4,050 (14.9)	6,240 (22.9)

COPD, chronic obstructive pulmonary disease, and emphysema.

Data from 386 community health centers in 19 states (AK, CA, FL, HI, KS, MD, MN, MO, MT, NC, NM, NV, OH, OR, RI, TX, WA, WI). The retrospective cohort of established patients included those who were uninsured at their last visit pre-ACA (2012 to 2013) and gained insurance coverage post-ACA (2014 to 2015). Conditions identified by ICD 9/10 codes in patients' problem lists or encounter diagnoses based on the Henry J Kaiser Family Foundation list of definable conditions.

**Table 3.**

Prevalence of Top 5 Conditions Pre- and Post-ACA, Among a Cohort of Established Community Health Center Patients Pre- and Post-Implementation of the Affordable Care Act (ACA) Insurance Expansions in 2014, by Race/Ethnicity

	Non-Hispanic White (N = 29,764)		Hispanic (N = 30,296)		Non-Hispanic Black (N = 13,090)	
	Pre, n (%)	Post, n (%)	Pre, n (%)	Post, n (%)	Pre, n (%)	Post, n (%)
Alcohol and drug abuse	4,576 (15.4)	7,645 (25.7)	1,025 (3.4)	1,881 (6.2)	1,111 (8.5)	1,973 (15.1)
Asthma, COPD	5,561 (18.7)	7,960 (26.7)	2,518 (8.3)	3,697 (12.2)	1,653 (12.6)	2,314 (17.7)
Diabetes	3,433 (11.5)	4,212 (14.2)	4,661 (15.4)	5,680 (18.7)	2,388 (18.2)	2,933 (22.4)
Mental health disorders	12,807 (43.0)	16,666 (56.0)	6,657 (22.0)	9,612 (31.7)	2,380 (18.2)	3,619 (27.6)
Obesity	4,743 (15.9)	7,186 (24.1)	4,850 (16.0)	7,391 (24.4)	2,480 (18.9)	3,820 (29.2)

COPD, chronic obstructive pulmonary disease, & emphysema.

Data from 386 community health centers in 19 states (AK, CA, FL, HI, KS, MD, MN, MO, MT, NC, NM, NY, OH, OR, RI, TX, WA, WI). The retrospective cohort of established patients included those who were uninsured at their last visit pre-ACA (2012 to 2013) and gained insurance coverage post-ACA (2014 to 2015). Conditions identified by ICD 9/10 codes in patients' problem lists or encounter diagnoses based on the Henry J Kaiser Family Foundation list of definable conditions.